

## Ecopsychosocial Interventions in Cognitive Decline and Dementia

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American Journal of Alzheimer's  
Disease & Other Dementias

**Ecopsychosocial Interventions in Cognitive Decline and  
Dementia: a new terminology and a new paradigm**

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Review

**Ecopsychosocial Interventions in Cognitive Decline and Dementia: a new terminology and a new paradigm**

**Introduction**

Governments and helping organizations globally are anticipating, with anxiety and trepidation, the enormous cost in both quality of life and currency of what many call the impending tsunami of Alzheimer’s—a condition associated with aging. The number of persons with Alzheimer’s and other forms of dementia in the world is expected to increase from 36 million people at the present time to 115 million in 2050. Consequently associated costs are anticipated to increase from an estimated \$655 billion dollars annually worldwide at the present time to nearly \$2 trillion dollars annually at mid-century.<sup>1</sup> While investments are being made in the search for a pharmacological solution to Alzheimer’s—a relatively small financial investment in terms of the dimension of the problem—investment into what are popularly called *nonpharmacological* interventions lags much farther behind.<sup>2</sup>

Nonpharmacological interventions that have been developed for persons with Alzheimer’s include: cultural events, such as guided museum programs for persons with cognitive challenges<sup>3</sup>; community efforts, such as alerting residents to the needs of persons with dementia living in their community; designing environments with recognizable landmarks that help persons with dementia find their way<sup>4</sup>; creative projects, such as group story writing that provides a sense of achievement<sup>5</sup>; and educational efforts, such as teaching family members to better interpret behaviors of their loved ones.

Initiatives such as those described above and many others with similar purposes, aim to replace maladaptive behavioral symptoms such as the four “A”s of Alzheimer’s<sup>6</sup>—anxiety, agitation, aggression, and apathy—with socially engaging behaviors. Consequently *nonpharmacological* interventions are on the front line of support for the improvement of the quality of life of persons with Alzheimer’s. In this publication, we propose that *nonpharmacological* interventions for persons with Alzheimer’s deserve formal recognition and support and therefore ought to be identified by a more positive nomenclature. A more proper and positive nomenclature for this field of research and practice will ultimately assist in achievements such as the reduction of conditions which lead to care in much more costly, and frequently, much less satisfying, health-care environments<sup>7</sup>. The more such positive interventions cut the costs of care and increase the satisfaction and psychological and physical health of both persons with dementia and those who care for and about them, the greater the savings for the society. If *nonpharmacological* interventions reduce the global monetary costs of care for persons living with Alzheimer’s today by only 5%, this saves governments, health systems, and individuals world-wide nearly \$33 billion dollars annually.<sup>8</sup>

**The ecopsychosocial approach**

There are important reasons why global investment in research into these humanistically valuable and potentially cost-effective “nonpharmacologic” approaches lags so far behind investment in pharmacologic treatments. We believe one reason is the lack of a clear, positively formulated definition of this field of research and intervention. Other reasons for the relative paucity of research investment may include significant methodological challenges to carrying out *nonpharmacological* research and the fact that *nonpharmacological* interventions often have little commercial viability. Exploratory studies that indicate positive outcomes of *nonpharmacological* interventions are often underfunded and subsequently discounted as not rigorous enough.

To overcome the first of these challenges—lack of a clear, positively formulated, definition—we propose to introduce the positive and inclusive term—*ecopsychosocial*—to replace the term “*nonpharmacological*” in both research literature and common parlance. Instead of defining this research area in terms of what it is not—not pharmaceutical—the term *ecopsychosocial* incorporates the full breadth and complexity of this area of inquiry and practice which is not clearly specified by the term “*nonpharmacological*.” Use of the term *nonpharmacological* raises ethical and practical issues as well as being conceptually inelegant; it is a commonly accepted shortcut that does not adequately describe the phenomena it refers to; a short cut, to continue the metaphor, that may create more problems for the entity it seeks to describe than a more direct and apposite description.

### The Challenges Created by Labeling

Labeling an intervention *nonpharmacological* means simply that it does not include pharmaceuticals in its protocol, framing such interventions in negative terms—as what they are not—rather than identifying the nature of what the intervention actually is. While the term *nonpharmacological* is gaining traction in the professional literature, employing it to describe a wide range of evidence-based programs such as caregiver training to assist in the understanding of the dementia process<sup>9</sup>, adaptive technologies that help the person communicate, the effects of personal care staff wearing street clothes instead of uniforms<sup>10</sup>, and interactive improvisational drama programs which engage persons’ creativity<sup>11</sup>, is both imprecise and undervalues the positive nature of the interventions.

Use of the label *nonpharmacological* to describe major shifts in the social milieu through counseling and support to assist family members to understand and live with the effects of dementia<sup>12</sup>, activity based drama and art interactions in which residents choose their own subject matter<sup>13</sup>, and environmental interventions, such as creating home-like settings to help residents adapt more easily to change<sup>14</sup>, fails to recognize that these interventions may be of greater significance and effectiveness in comparison with existing pharmacologic treatments<sup>15</sup>, and are at the very least complementary to conventional treatment. In treatment of behavioral and psychological symptoms of dementia (BPSD), so called *nonpharmacological* interventions can reduce or even eliminate the use of potentially harmful medications<sup>16 17 18 19 20 21</sup>.

Ethical and practical questions raised by the use of the term *nonpharmacological* include: How does the use of a nonspecific and inexact label limit financial resources for research? Does such a label make it unnecessarily difficult to acquire and compare potentially significant research data and evidence? Does using a negative label limit access to treatments that might provide those with dementia and their partners a higher quality of life?

The term *nonpharmacological* is increasingly used in medical research literature. Scholarly and professional articles appear regularly on a range of *nonpharmacological* interventions to treat health conditions such as recovery from heart transplants<sup>22</sup>, gastrointestinal disorders<sup>23</sup>, fibromyalgia<sup>24</sup>, premenstrual syndrome<sup>25</sup>, hypertension<sup>26</sup>, and children's postoperative pain<sup>27</sup>.

A similar increase in interest in nonpharmacological approaches is evident in dementia research, an example of which is a recent article by Cohen-Mansfield in which she employs the acronym "NPHI" for *Nonpharmacological Interventions*<sup>28</sup>. Other recent articles on *nonpharmacological* interventions in dementia include studies of agitation<sup>29</sup><sup>30</sup>, the effects of music<sup>31</sup>, delirium<sup>32</sup> and Huntington's related dementia<sup>33</sup>. As the term *ecopsychosocial* is increasingly adopted, it will be imperative to cross-reference the two terms *nonpharmacological* and *ecopsychosocial* in future publications

**Finding a Better Name**

Often employed interchangeably with *nonpharmacological*, the term *psychosocial* refers to outcomes of interventions aimed at improving a person's psychological state or social situation. However, many effective *nonpharmacological* interventions imply mechanisms which are beyond the boundaries of this terminology. For example, the effect of exercise to reduce obesity and dementia risk is a biological treatment. The term *bio-psychosocial* has also been used<sup>34</sup> but it implies a more circumscribed view of biology (molecular and pharmacological) whereas *ecopsychosocial* implies a macro view including the environment and the public health context.

The terms *psychosocial* and *bio-psychosocial* clearly do not encompass the broad array of what are now being called *nonpharmacological* interventions. While intergenerational charter schools where elders with dementia teach and learn from younger students,<sup>35</sup> and museum visit programs where those with dementia look at and discuss works of art in normal settings, improve the quality of life for persons with dementia and have *psychosocial* effects, such programs encompass much more. Environmental contextual change is integral to such actions and programs. The impact of such interventions is on context and environment and not simply on the individual living with the disease. Notions of context and the broader impact of change are missing from current nomenclature. *Psychosocial*, for example, describes some effects of some interventions on individuals but the terminology does not adequately address the impact of contextual changes brought about by access to safe therapeutic gardens or introducing a new object such as a "memory book" into the setting with structured visual memory-jogging material<sup>36</sup>, employing computer tablets for communication, or

introducing music and art appreciation as a way to engage people with dementia in meaningful discussion.

### ***Ecopsychosocial*—a Term to Cut the Gordian Knot**

Using the prefix *eco-*, as employed in the term *ecological*, begins to resolve the insular terminology dilemma. “Ecological” refers to “the interrelationship of organisms and their environment” and to the study of “the relationships between a group of living things and their environment.”<sup>37</sup> Frequently employed in biology, sociology, and psychology to include contextual factors, the term “eco-,”—etymologically rooted in the Greek term for house or household (*oikes*)<sup>38</sup>—rectifies the current terminological deficiency. Since many interventions presently considered *nonpharmacological* are concerned with changing the context or environment of persons with dementia, it is clear that a reference to “context” is advantageous if not essential in defining this approach.

We believe that the term *ecopsychosocial* (EPS) provides a significant improvement over the present term *nonpharmacological*. The new term positively delimits an expanding category of therapeutics and serves to draw together for research purposes a broad group of interventions to treat dementia.

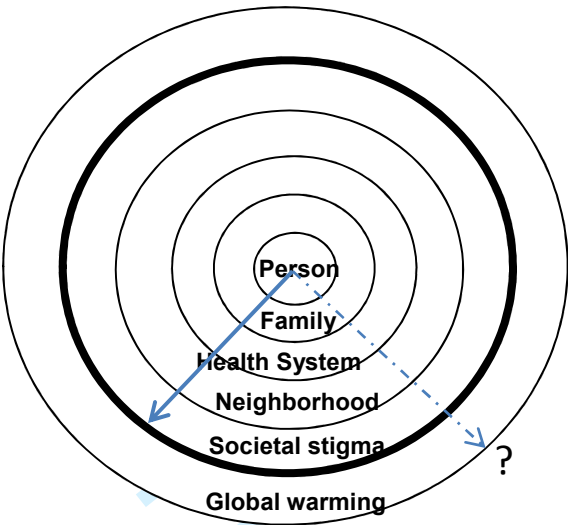
The value of the *ecopsychosocial* terminology for the scientific community is that identifying a field with clear and, in this case, potentially broader boundaries and components should result in more fruitful professional discussion while providing a vehicle for structured research support. As the field of *ecopsychosocial studies* of cognitive decline and dementia is increasingly recognized, subject matter, academic curricula, and research protocols particularly suited to the field are likely to emerge. Similarly, results of related research projects can more easily be compared—thus contributing to a critical mass of comparable data to be used in resource allocation and policy making.

### **Defining the Range of “*ecopsychosocial*” (EPS) Impacts & Outcomes**

Including environment as a factor raises the question of what scale or range of environment ought to be considered when defining the environmental context of *ecopsychosocial* interventions. What is the environmental range of the “dementia problem”? Figure 1 provides a conceptual diagram of the *ecopsychosocial* approach.



Clearly the person at the center of the diagram, his or her family, and their health system are part of the “dementia person’s” environment. But what about the



**Figure 1: Environmental Range of Ecopsychosocial Interventions in**

neighborhood and larger community? Community resources are important because those living with dementia are more likely to use the physical and commercial environments near their homes and in their community if they feel welcome and if neighbors are trained to understand and respond to their needs. Social policies and practices need to resist the culturally defined social stigma associated with the disability, so that this condition is less of a barrier to social integration.

Local government regulations that affect barrier-free streets, parks, and public transit as well as environmental requirements, codes, and standards for special-needs residential environments are directly relevant to the context within which people with dementia exist. The argument can also be made that urbanization, air pollution, the way our food is handled and sold, and global warming are all part of the dementia person’s environment. However, expanding the definition of *ecopsychosocial* context beyond the context of community and society runs the risk of diluting the discipline beyond practical bounds. Every concept, including *ecopsychosocial*, needs to evolve through debate, research, and government action. We propose to include the study of social attitudes toward persons with dementia and the stigma associated with dementia, as well as social policies and investment in dementia, as relevant contextual limits at this time.

In summary, *nonpharmacological* approaches make up a dynamic and expanding field of treatment and research with positive effects on illnesses and diseases including dementia. The scientific and practice communities need better and more positive language to describe this growing field. While the term *nonpharmacological* emphasizes what the field is not and forces the definition to center in and around conventional pharmacological therapies, the term we propose, *ecopsychosocial*, incorporates environmental and contextual influences and emphasizes the importance

and positive nature of a broad range of interventions in the lives of those living with dementia.

*Ecopsychosocial* is a practical and conceptually elegant term to replace the term *nonpharmacological* in dementia and other studies. *Ecopsychosocial* avoids defining phenomena by what they are not and, more significantly, includes the broad range of subject matter and research interest actually included in the overall term, especially contextual issues and environmental design. We urge and welcome the professional community's adoption of the new recommended terminology as well as ongoing commentary and study of these matters.

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<sup>2</sup> According to the National Institute of Health's Research Portfolio Online Reporting tools (RePORT), 1659 grants were awarded under the NIH spending category of dementia in fiscal year 2013. In a random sample of 100 of these awards only 2% of grant awards and only 1.6% of monetary funding (\$468,345 of \$29,741,932 for the 100 studies) was awarded to nonpharmacological studies (the remaining \$29,273,587 for the 100 studies awarded to basic science and pharmacological research.) The total award amount for all 1659 awards was \$648,317,093 with an extrapolated expenditure of 1.6% for 33 studies of nonpharmacological subject matter totaling \$10,054,549. *Report.nih.gov/categorical\_spending.aspx* (accessed June 26, 2014)

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## Ecopsychosocial Interventions in Cognitive Decline and Dementia: a new terminology and a new paradigm<sup>a</sup>

*John Zeisel<sup>b</sup>, Barry Reisberg<sup>c</sup>, Peter Whitehouse<sup>d</sup>, Robert Woods<sup>e</sup>, Ad Verheul<sup>f</sup>*

### Introduction

Governments and helping organizations globally are anticipating, with anxiety and trepidation, the enormous cost in both quality of life and currency of what many call the impending tsunami of ~~Alzheimer's dementia~~—a condition associated with aging. The number of persons with ~~Alzheimer's and other forms of~~ dementia in the world is expected to increase from 36 million people at the present time to 115 million in 2050. Consequently associated costs ~~are anticipated~~ can be calculated to increase from an estimated \$655 billion dollars annually worldwide at the present time to nearly \$2 trillion dollars annually at mid-century.<sup>1</sup> While investments are being made in the search for a pharmacological solution to ~~Alzheimer's dementia~~—a relatively small financial investment in terms of the dimension of the problem—investment into what are popularly called *nonpharmacological* interventions lags ~~much farther~~ far behind.<sup>2</sup>

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<sup>a</sup> This paper is part of a two-year series of international consensus symposia organized in Spain and Portugal by the WISDEM network. Members of the symposia included: Jiska Cohen-Mansfield (Israel), Torhild Holthe (Norway), Renata Avila (Brazil), Cameron Camp (USA), Li-Chan Lin (Taiwan), Joel Belmin (France), Anne Basting (USA), Sean Caulfield (USA), Marily Cintra (Australia), Elisabetta Farina (Italy), John Killick (UK), Richard Taylor (USA), Magda Tsolaki (Greece), Yeunsook Lee (Korea), Maggie Calkins (USA), Mary Marshall (Scotland), Richard Fleming (Australia), Sibylle Heeg (Germany), Kevin Charras (France), Anne Margriet Pot (Holland), Jesus Favela (Mexico), Alex Mihailidis (Canada), Suzanne Martin (Northern Ireland), Topo Päävi (Finland), Maria Parsons (UK), Irina Roschina (Russia), Ken Sakamura (Japan) as well as the authors, John Zeisel (USA), Barry Reisberg (USA), Peter Whitehouse (USA), Robert Woods (UK), and Ad Verheul (Holland).

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<sup>e</sup> Bangor University, Wales, UK

<sup>f</sup> 's Heeren Loo, Holland & Founder of Snoezelen Therapy.

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~~Initiatives such as those described above~~ These and many ~~others~~ other initiatives with similar purposes, aim to replace maladaptive behavioral symptoms such as the four “A”s of Alzheimer’s<sup>8</sup>—anxiety, agitation, aggression, and apathy—with socially engaging behaviors. Consequently *nonpharmacological* interventions are on the front line of support for the improvement of the quality of life of persons with ~~Alzheimer’s. In dementia. We assert in~~ this publication, ~~we propose~~ that *nonpharmacological* interventions for persons with ~~Alzheimer’s dementia~~ deserve formal recognition and support and therefore ought to be identified by a more ~~positive~~ precise and distinctive nomenclature. A more ~~proper and positive~~ precise nomenclature for this field of research and practice will ultimately assist in achievements ~~such as the reduction of that include reducing~~ conditions ~~which that~~ lead to care in ~~much~~ more costly, and frequently, ~~much~~ less satisfying, health-care environments<sup>9</sup>. The more such positive interventions cut the costs of care and increase ~~the~~ satisfaction and psychological and physical health of both persons with dementia and those who care for and about them, the greater the savings for ~~the~~ society. If *nonpharmacological* interventions reduce the global monetary costs of care for persons living with ~~Alzheimer’s dementia~~ today by only 5%, ~~this saves~~ governments, health systems, and individuals world-wide will save nearly \$33 billion dollars annually.<sup>10</sup>

**The ecopsychosocial approach**  
**The Need for a Distinct Field of Inquiry**

There are important reasons why global investment in research into these humanistically valuable and potentially cost-effective “nonpharmacologic” approaches

lags so far behind investment in pharmacologic treatments. ~~We believe one~~One reason is the lack of a clear, ~~positively formulated~~ definition of ~~this~~these efforts as a distinct field of research and intervention. Other reasons for the relative paucity of research investment ~~may~~ include significant methodological challenges to carrying out *nonpharmacological* research and the fact that *nonpharmacological* interventions often have little commercial viability. Exploratory studies ~~that indicate~~indicating positive outcomes of *nonpharmacological* interventions are often underfunded and subsequently discounted as not rigorous enough.

To overcome the first of these challenges—lack of a ~~clear, positively~~clearly formulated, definition—we propose ~~to introduce the positive and inclusive~~ term—*ecopsychosocial*—to replace the term “*nonpharmacological*” in both research literature and common parlance. Instead of defining this research area in terms of what it is not—not pharmaceutical—the term *ecopsychosocial* ~~inclusively~~ incorporates the full breadth and complexity of this area of inquiry and practice ~~which is not clearly specified by~~as ~~reflected in~~ the term “*nonpharmacological*.” ~~many studies being carried out and interventions currently in practice~~. Use of the term *nonpharmacological* raises ethical and practical issues as well as being conceptually inelegant; it is a commonly accepted shortcut that does not adequately describe the phenomena it refers to; a short cut, to continue the metaphor, that may ~~create~~lengthen the journey by creating more problems for the entity it seeks to describe than a more direct and apposite description.

### ~~The Challenges Created by~~Labeling: An Epistemological Challenge

Labeling an intervention *nonpharmacological* means simply that it does not include pharmaceuticals in its protocol, ~~framing~~. ~~Rather than identifying the nature of~~ such interventions ~~—by what they actually are—the term frames the interventions~~ in negative terms—~~as by~~ what they are not—~~rather than identifying the nature of what the intervention actually is~~. While, ~~Although~~ the term *nonpharmacological* is ~~both imprecise and undervalues the positive nature of such interventions, it is~~ gaining traction in the professional literature, ~~employing it~~increasing the urgency for a new label. The term is ~~increasingly being employed~~ to describe a wide range of evidence-based programs



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such as caregiver training to assist in ~~the~~ understanding ~~of~~ the dementia process<sup>11</sup>, adaptive technologies that help the person communicate, the effects of personal care staff wearing street clothes instead of uniforms<sup>12</sup>, and interactive improvisational drama programs which engage persons' creativity<sup>13</sup>, ~~is both imprecise and undervalues the positive nature of the interventions.~~

~~Use of the~~ The label *nonpharmacological* ~~is also being employed~~ to describe major shifts in the social milieu ~~throughof persons with dementia such as~~ counseling and support ~~to assistof~~ family members ~~to assist them~~ to understand and live with the effects of dementia<sup>14</sup>, activity based drama and art interactions in which residents choose their own subject matter<sup>15</sup>, and environmental interventions, such as creating home-like settings to help residents adapt more easily to change<sup>16</sup>. ~~Such labeling~~ fails to recognize that these interventions may be of greater significance and effectiveness in comparison with existing pharmacologic treatments<sup>17</sup>, ~~and are~~ at the very least ~~should be considered~~ complementary to conventional treatment. In treatment of behavioral and psychological symptoms of dementia ~~(BPSD)~~, so called *nonpharmacological* interventions ~~can have been shown to~~ reduce ~~orand~~ even eliminate the use of ~~medications which on occasion~~ potentially ~~harmful medications~~ ~~may have deleterious adverse effects.~~<sup>18 19 20 21 22 23</sup>

~~Ethical and practical questions raised by the use of the term nonpharmacological include: How does the use of a nonspecific and inexact label limit financial resources for research? Does such a label make it unnecessarily difficult to acquire and compare potentially significant research data and evidence? Does using a negative label limit access to treatments that might provide those with dementia and their partners a higher quality of life?~~

~~The term nonpharmacological~~ In dementia research there is increasingly used in medical research literature. Scholarly and professional articles appear regularly on a range of *nonpharmacological* interventions to treat health conditions such as recovery from heart transplants<sup>24</sup>, gastrointestinal disorders<sup>25</sup>, fibromyalgia<sup>26</sup>, premenstrual syndrome<sup>27</sup>, hypertension<sup>28</sup>, and children's postoperative pain<sup>29</sup>.

A similar clearly an increase in interest in nonpharmacological approaches is evident in dementia research, an example of which is a recent. A significant article by Cohen-Mansfield in which she employs the acronym "NPHI" for Nonpharmacological Interventions<sup>30</sup> is a prime example. Other recent articles on *nonpharmacological* interventions in dementia include studies of agitation<sup>31 32</sup>, the effects of music<sup>33</sup>, delirium<sup>34</sup>, and Huntington's related dementia<sup>35</sup>.

The term *nonpharmacological* is also increasingly used in basic medical research literature, not only research related to dementia. Scholarly and professional articles appear regularly describing a range of *nonpharmacological* interventions to treat health conditions such as recovery from heart transplants<sup>36</sup>, gastrointestinal disorders<sup>37</sup>, fibromyalgia<sup>38</sup>, premenstrual syndrome<sup>39</sup>, hypertension<sup>40</sup>, and children's postoperative pain<sup>41</sup>. As the term *ecopsychosocial* is increasingly adopted, it will be imperative to cross-reference the two terms *nonpharmacological* and *ecopsychosocial* in future publications.

Ethical and practical questions are raised by the use of the term *nonpharmacological*. These include: How does the use of a nonspecific and inexact label limit financial resources for research? Does such a label make it unnecessarily difficult to acquire and compare potentially significant research data and evidence? Does using a negative label limit access to treatments that might provide those with dementia and their partners a higher quality of life?

**Finding** A similar shift in terminology with an equally difficult transition for the field is the way researchers and clinicians are avoiding the term "behaviors" when referring to the many, often socially disruptive, ways in which those living with dementia express themselves or communicate their needs.<sup>42</sup> While this transition is taking time and effort, the shift eventually benefits all those with dementia who are presently being treated as if their "behaviors" have little to do with intent and meaning and are merely phenomena to eliminate with whatever means possible.

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**Seeking a Better Name**

Often employed interchangeably with *nonpharmacological*, the term *psychosocial* refers to outcomes of interventions aimed at improving a person’s psychological state or social situation. ~~However, many effective nonpharmacological interventions imply mechanisms which are beyond the boundaries of this terminology. For example, the effect of exercise to reduce obesity and dementia risk is a biological treatment. The term bio-psychosocial has also been used<sup>43</sup> but it implies a more circumscribed view of biology (molecular and pharmacological) whereas ecopsychosocial implies a macro view including the environment and the public health context~~As noted by Vesse et al<sup>44</sup>, the American Psychiatric Association has a formal definition for psychosocial interventions: actions that “aim to improve quality of life and psychological and social functioning, and to maximize function in the context of existing deficits”<sup>45</sup> but there is no similar definition for “nonpharmacological” interventions.

The terms *psychosocial* and *bio-psychosocial* ~~are often used interchangeably with the term nonpharmacological, but~~ clearly do not encompass the broad array of what are now being called *nonpharmacological* interventions. ~~While~~Programs such as intergenerational charter schools where elders with dementia teach and learn from younger students;<sup>46</sup> and museum visit programs where those with dementia look at and discuss works of art in normal settings;<sup>47</sup> improve the quality of life for persons with dementia and have *psychosocial* effects, ~~such but these~~ programs encompass much more. Environmental contextual change which is integral to such actions and programs is clearly not included under the umbrella of psychosocial effects. The impact of such interventions is on context and environment and not simply on the individual living with the disease. Notions of context and the broader impact of change are missing from current nomenclature. *Psychosocial*, ~~for example,~~ describes some effects of some interventions on individuals but the terminology does not adequately address the impact of contextual changes brought about by access to safe therapeutic gardens or introducing a new object such as a “memory book” into the setting with structured visual memory-jogging material<sup>48</sup>, employing computer tablets for communication, or

introducing music and art appreciation as a way to engage people with dementia in meaningful discussion.

The name change from *nonpharmacological* to *ecopsychosocial* interventions should also help dissolve the narrow perception that the only hope for quality of life for persons with dementia lies somewhere in a vague future when a cure is discovered. Because the term “nonpharmacological” does not adequately suggest that there are many interventions readily and easily available to individuals and families who provide care for persons with dementia, a new descriptive term reinforces a more user-inclusive approach to care.

### ***Ecopsychosocial—*a Term to Cut the Gordian Knot**

Using the prefix *eco-*, as employed in the term *ecological*, begins to resolve the insular terminology dilemma. “Ecological” refers to “the interrelationship of organisms and their environment” and to the study of “the relationships between a group of living things and their environment.”<sup>49</sup> Frequently employed in biology, sociology, and psychology to include contextual factors, the term “eco-,”—etymologically rooted in the Greek term for house or household (*oikos*)<sup>50</sup>—rectifies the current terminological deficiency. Since many interventions presently considered *nonpharmacological* are concerned with changing the context or environment of persons with dementia, it is clear that a reference to “context” is advantageous if not essential in defining this approach.

We believeIn the field of environmental psychology which plays a major role in nonpharmacological treatment for dementia, the work of J. J. Gibson<sup>51</sup> highlights the theory of “affordances” and “niches” in what Gibson labeled “ecological psychology.” Affordances are the opportunities environments offer—from the scale of a teacup to that the of a city and beyond—that are directly perceived and acted upon by users. Niches—ecological niches—represent a set of affordances in which individuals can choose to express their needs or not, according to their abilities and the environmental constraints they naturally face. This approach holds particular hope for people with

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dementia because no cognitive analytic interpretation is necessary to read and negotiate such environments.

The work of prominent gerontologists and environmental psychologists with expertise in the role the physical environment plays in the lives of persons with dementia has led to conceptual constructs demonstrating the effects of the physical environment on the health and well-being of elders with dementia. One of these, Lawton’s “environmental press model”<sup>52</sup>, describes how a middle level of environmental support—neither too stressful nor too supportive—provides the healthiest level of challenge to older users. Bronfenbrenner’s “ecological model”<sup>53</sup>, Algase’s “need driven behavior model”<sup>54</sup>, and the work of Cohen-Mansfield<sup>55</sup> provide other critical examples. This body of work provides further justification for including the prefix “eco” in any replacement term for the label nonpharmacological.

Employing the prefix “eco” as we suggest, presents a potential conceptual trap. Since “eco” has been so much used by those who promote and defend the natural environment, the use of this prefix may conjure up in some readers’ minds images of the outdoors and protesting against global warming. Nevertheless, we suggest its use because of its conceptual elegance and origins.

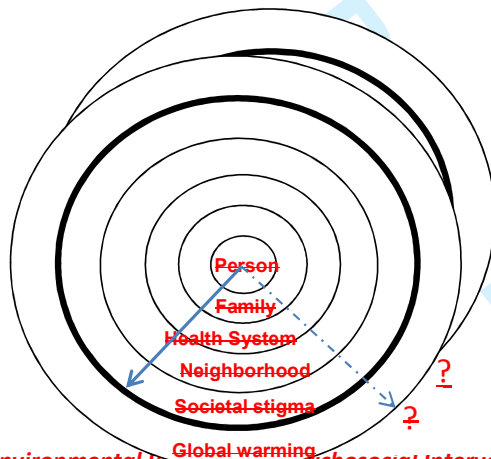
The term *ecopsychosocial* (*EPS*) provides a significant improvement over the present term *nonpharmacological*. The new term, positively ~~delimits~~*delimiting* an expanding category of therapeutics and ~~serves~~*serving* to draw together for research purposes a broad group of interventions to treat dementia.

The value of the ecopsychosocial terminology for the scientific community is that identifying a field with clear and, in this case, potentially broader boundaries and components should result in more fruitful professional *collaboration and* discussion, while providing a vehicle for structured research support. As the field of *ecopsychosocial studies* of cognitive decline and dementia is increasingly recognized, subject matter, academic curricula, and research protocols particularly suited to the field

are likely to emerge. Similarly, results of related research projects can more easily be compared—thus contributing to a critical mass of comparable data to be used in resource allocation and policy making.

### **Defining/Determining the Range of “ecopsychosocial” (EPS) Impacts & Ecopsychosocial” Outcomes**

Including environment as a factor raises the question of what scale or range of environment ought to be considered when defining the environmental context of *ecopsychosocial* interventions. What is the environmental range of the “dementia problem”? Figure 1 provides a conceptual diagram of the *ecopsychosocial* approach.



**Figure 1: Environmental Range of Ecopsychosocial Interventions in Dementia**

**Figure 1: Environmental Range of Ecopsychosocial Interventions in Dementia**

Clearly the person at the center of the diagram, his or her family, and their health system are part of the “dementia person’s” environment. But what about the neighborhood and larger community? Community resources are important because those living with dementia are more likely to use the physical and commercial environments near their homes and in their community if they feel welcome and if neighbors are trained to understand and respond to their needs. Social policies and



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practices need to resist the culturally defined social stigma associated with the disability, so that ~~this condition~~dementia is ~~less of no longer~~ a barrier to social integration.

Local government regulations that affect barrier-free streets, parks, and public transit as well as environmental requirements, codes, and standards for special-needs residential environments are directly relevant to the context within which people with dementia ~~exist~~live. The argument can ~~also~~ be made that urbanization, air pollution, the way our food is handled and sold, and global warming are all part of the dementia person's environment. However, expanding the definition of *ecopsychosocial* context beyond ~~the context of~~ community and society runs the risk of diluting the discipline beyond practical bounds. ~~Every concept, including ecopsychosocial, needs to evolve through debate, research, and government action.~~ We propose to include the study of social attitudes toward persons with dementia and the stigma associated with dementia, as well as social policies and investment in dementia, as relevant contextual limits at this time.

In summary, *nonpharmacological* approaches make up a dynamic and expanding field of treatment and research with positive effects on illnesses and diseases including dementia. The scientific and practice communities need better and more positive language to describe this growing field. While the term *nonpharmacological* emphasizes what the field is not and forces the definition to center in and around conventional pharmacological therapies, the term ~~we propose, ecopsychosocial,~~ incorporates environmental and contextual influences and emphasizes the importance and positive nature of a broad range of interventions in the lives of those living with dementia.

*Ecopsychosocial* is a practical and conceptually elegant term to replace the term *nonpharmacological* in dementia and other studies. *Ecopsychosocial* avoids defining phenomena by what they are not and, more significantly, includes the broad range of subject matter and research interest ~~actually included in embodied within~~ the overall term, ~~especially such as~~ contextual issues and environmental design. Every concept, including ecopsychosocial, needs to evolve through debate, research, and in this

context, regulatory and governmental action. We urge and welcome the professional community's adoption of ~~the new recommended~~this terminology, as well as ongoing commentary and study of these matters.

For Peer Review

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<sup>1</sup> World Health Organization (WHO) & ~~Alzheimer's disease~~Alzheimer's Disease International (ADI) (2012), Dementia: a public health priority, World Health Organization, Geneva, Page 2, ISBN: 9789241564458.

<sup>2</sup> According to the National Institute of Health's Research Portfolio Online Reporting tools (RePORT), 1659 grants were awarded under the NIH spending category of dementia in fiscal year 2013. In a random sample of 100 of these awards only 2% of grant awards and only 1.6% of monetary funding (\$468,345 of \$29,741,932 for the 100 studies) was awarded to nonpharmacological studies (the remaining ~~\$29,273,587~~ for the 100 studies was awarded to basic science and pharmacological research.) The total award amount for all 1659 awards was \$648,317,093 with an extrapolated expenditure of 1.6% for 33 studies of nonpharmacological subject matter totaling \$10,054,549. Report.nih.gov/categorical\_spending.aspx (accessed June 26, 2014)

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# Ecopsychosocial Interventions in Cognitive Decline and Dementia: a new terminology and a new paradigm<sup>a</sup>

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## Introduction

Governments and helping organizations globally are anticipating, with anxiety and trepidation, the enormous cost in both quality of life and currency of what many call the impending tsunami of dementia—a condition associated with aging. The number of persons with dementia in the world is expected to increase from 36 million people at the present time to 115 million in 2050. Consequently associated costs can be calculated to increase from an estimated \$655 billion dollars annually worldwide at the present time to nearly \$2 trillion dollars annually at mid-century.<sup>1</sup> While investments are being made in the search for a pharmacological solution to dementia—a relatively small financial investment in terms of the dimension of the problem—investment into what are popularly called *nonpharmacological* interventions lags far behind.<sup>2</sup>

Nonpharmacological interventions developed for persons with dementia include: cultural events, such as guided museum programs for persons with cognitive challenges<sup>3</sup>; community efforts, such as training and alerting residents to recognize and respond to the needs of persons with dementia living in their community; designing environments with recognizable landmarks that, by linking to the brain's cognitive map, help persons

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with dementia find their way<sup>4</sup>; creative projects, such as group story writing that provides a sense of achievement<sup>5 6</sup>; cognitive training efforts that build on procedural learning abilities retained by persons with dementia<sup>7</sup>; and educational efforts, such as teaching family members to better interpret behaviors of their loved ones.

These and many other initiatives with similar purposes aim to replace maladaptive behavioral symptoms such as the four "A"s of Alzheimer's<sup>8</sup>—anxiety, agitation, aggression, and apathy—with socially engaging behaviors. Consequently *nonpharmacological* interventions are on the front line of support for the improvement of the quality of life of persons with dementia. We assert in this publication that *nonpharmacological* interventions for persons with dementia deserve formal recognition and support and therefore ought to be identified by a more precise and distinctive nomenclature. A more precise nomenclature for this field of research and practice will ultimately assist in achievements that include reducing conditions that lead to care in more costly, and frequently less satisfying, health-care environments<sup>9</sup>. The more such positive interventions cut the costs of care and increase satisfaction and psychological and physical health of both persons with dementia and those who care for and about them, the greater the savings for society. If *nonpharmacological* interventions reduce the global monetary costs of care for persons living with dementia today by only 5%, governments, health systems, and individuals world-wide will save nearly \$33 billion dollars annually.<sup>10</sup>

**The Need for a Distinct Field of Inquiry**

There are important reasons why global investment in research into these humanistically valuable and potentially cost-effective “nonpharmacologic” approaches lags so far behind investment in pharmacologic treatments. One reason is the lack of a clear definition of these efforts as a distinct field of research and intervention. Other reasons for the relative paucity of research investment include significant methodological challenges to carrying out *nonpharmacological* research and the fact that *nonpharmacological* interventions often have little commercial viability. Exploratory

studies indicating positive outcomes of *nonpharmacological* interventions are often underfunded and subsequently discounted as not rigorous enough.

To overcome the first of these challenges—lack of a clearly formulated definition—we propose the term—*ecopsychosocial*—to replace the term “*nonpharmacological*” in both research literature and common parlance. Instead of defining this research area in terms of what it is not—not pharmaceutical—the term *ecopsychosocial* inclusively incorporates the full breadth and complexity of this area of inquiry and practice as reflected in the many studies being carried out and interventions currently in practice. Use of the term *nonpharmacological* raises ethical and practical issues as well as being conceptually inelegant; it is a commonly accepted shortcut that does not adequately describe the phenomena it refers to; a short cut, to continue the metaphor, that may lengthen the journey by creating more problems for the entity it seeks to describe than a more direct and apposite description.

### **Labeling: An Epistemological Challenge**

Labeling an intervention *nonpharmacological* means simply that it does not include pharmaceuticals in its protocol. Rather than identifying the nature of such interventions—by what they actually are—the term frames the interventions in negative terms—by what they are not. Although the term *nonpharmacological* is both imprecise and undervalues the positive nature of such interventions, it is gaining traction in the professional literature, increasing the urgency for a new label. The term is increasingly being employed to describe a wide range of evidence-based programs such as caregiver training to assist in understanding the dementia process<sup>11</sup>, adaptive technologies that help the person communicate, the effects of personal care staff wearing street clothes instead of uniforms<sup>12</sup>, and interactive improvisational drama programs which engage persons’ creativity<sup>13</sup>.

The label *nonpharmacological* is also being employed to describe major shifts in the social milieu of persons with dementia such as counseling and support of family members to assist them to understand and live with the effects of dementia<sup>14</sup>, activity

based drama and art interactions in which residents choose their own subject matter<sup>15</sup>, and environmental interventions, such as creating home-like settings to help residents adapt more easily to change<sup>16</sup>. Such labeling fails to recognize that these interventions may be of greater significance and effectiveness in comparison with existing pharmacologic treatments<sup>17</sup>—and at the very least should be considered complementary to conventional treatment. In treatment of behavioral and psychological symptoms of dementia, so called *nonpharmacological* interventions have been shown to reduce and even eliminate the use of medications which on occasion potentially may have deleterious adverse effects.<sup>18 19 20 21 22 23</sup>

In dementia research there is clearly an increase in interest in nonpharmacological approaches. A significant article by Cohen-Mansfield in which she employs the acronym “NPHI” for Nonpharmacological Interventions<sup>24</sup> is a prime example. Other recent articles on *nonpharmacological* interventions in dementia include studies of agitation<sup>25 26</sup>, the effects of music<sup>27</sup>, delirium<sup>28</sup>, and Huntington’s related dementia<sup>29</sup>.

The term *nonpharmacological* is also increasingly used in basic medical research literature, not only research related to dementia. Scholarly and professional articles appear regularly describing a range of *nonpharmacological* interventions to treat health conditions such as recovery from heart transplants<sup>30</sup>, gastrointestinal disorders<sup>31</sup>, fibromyalgia<sup>32</sup>, premenstrual syndrome<sup>33</sup>, hypertension<sup>34</sup>, and children’s postoperative pain<sup>35</sup>. As the term *ecopsychosocial* is increasingly adopted, it will be imperative to cross-reference the two terms *nonpharmacological* and *ecopsychosocial* in future publications.

Ethical and practical questions are raised by the use of the term *nonpharmacological*. These include: How does the use of a nonspecific and inexact label limit financial resources for research? Does such a label make it unnecessarily difficult to acquire and compare potentially significant research data and evidence? Does using a negative label limit access to treatments that might provide those with dementia and their partners a higher quality of life?

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5 A similar shift in terminology with an equally difficult transition for the field is the way  
6 researchers and clinicians are avoiding the term “behaviors” when referring to the many,  
7 often socially disruptive, ways in which those living with dementia express themselves  
8 or communicate their needs.<sup>36</sup> While this transition is taking time and effort, the shift  
9 eventually benefits all those with dementia who are presently being treated as if their  
10 “behaviors” have little to do with intent and meaning and are merely phenomena to  
11 eliminate with whatever means possible.  
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### 19 Seeking a Better Name

20 Often employed interchangeably with *nonpharmacological*, the term *psychosocial* refers  
21 to outcomes of interventions aimed at improving a person’s psychological state or social  
22 situation. As noted by Vesse et al<sup>37</sup>, the American Psychiatric Association has a formal  
23 definition for psychosocial interventions: actions that “aim to improve quality of life and  
24 psychological and social functioning, and to maximize function in the context of existing  
25 deficits”<sup>38</sup> but there is no similar definition for “nonpharmacological” interventions.  
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33 The terms *psychosocial* and *bio-psychosocial* are often used interchangeably with the  
34 term *nonpharmacological*, but clearly do not encompass the broad array of what are  
35 now being called *nonpharmacological* interventions. Programs such as  
36 intergenerational charter schools where elders with dementia teach and learn from  
37 younger students<sup>39</sup> and museum visit programs where those with dementia look at and  
38 discuss works of art in normal settings<sup>40</sup> improve the quality of life for persons with  
39 dementia and have *psychosocial* effects, but these programs encompass much more.  
40 Environmental contextual change which is integral to such actions and programs is  
41 clearly not included under the umbrella of *psychosocial* effects. The impact of such  
42 interventions is on context and environment and not simply on the individual living with  
43 the disease. Notions of context and the broader impact of change are missing from  
44 current nomenclature. *Psychosocial* describes some effects of some interventions on  
45 individuals but the terminology does not adequately address the impact of contextual  
46 changes brought about by access to safe therapeutic gardens or introducing a new  
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object such as a “memory book” into the setting with structured visual memory-jogging material<sup>41</sup>, employing computer tablets for communication, or introducing music and art appreciation as a way to engage people with dementia in meaningful discussion.

The name change from *nonpharmacological* to *ecopsychosocial* interventions should also help dissolve the narrow perception that the only hope for quality of life for persons with dementia lies somewhere in a vague future when a cure is discovered. Because the term “nonpharmacological” does not adequately suggest that there are many interventions readily and easily available to individuals and families who provide care for persons with dementia, a new descriptive term reinforces a more user-inclusive approach to care.

***Ecopsychosocial—a Term to Cut the Gordian Knot***

Using the prefix *eco-*, as employed in the term *ecological*, begins to resolve the insular terminology dilemma. “Ecological” refers to “the interrelationship of organisms and their environment” and to the study of “the relationships between a group of living things and their environment.”<sup>42</sup> Frequently employed in biology, sociology, and psychology to include contextual factors, the term “eco-,”—etymologically rooted in the Greek term for house or household (*oikes*)<sup>43</sup>—rectifies the current terminological deficiency. Since many interventions presently considered *nonpharmacological* are concerned with changing the context or environment of persons with dementia, it is clear that a reference to “context” is advantageous if not essential in defining this approach.

In the field of environmental psychology which plays a major role in nonpharmacological treatment for dementia, the work of J. J. Gibson<sup>44</sup> highlights the theory of “affordances” and “niches” in what Gibson labeled “ecological psychology.” Affordances are the opportunities environments offer—from the scale of a teacup to that of a city and beyond—that are directly perceived and acted upon by users. Niches—ecological niches—represent a set of affordances in which individuals can choose to express their needs or not, according to their abilities and the environmental constraints they naturally

face. This approach holds particular hope for people with dementia because no cognitive analytic interpretation is necessary to read and negotiate such environments.

The work of prominent gerontologists and environmental psychologists with expertise in the role the physical environment plays in the lives of persons with dementia has led to conceptual constructs demonstrating the effects of the physical environment on the health and well-being of elders with dementia. One of these, Lawton's "environmental press model"<sup>45</sup>, describes how a middle level of environmental support—neither too stressful nor too supportive—provides the healthiest level of challenge to older users. Bronfenbrenner's "ecological model"<sup>46</sup>, Algase's "need driven behavior model"<sup>47</sup>, and the work of Cohen-Mansfield<sup>48</sup> provide other critical examples. This body of work provides further justification for including the prefix "eco" in any replacement term for the label nonpharmacological.

Employing the prefix "eco" as we suggest, presents a potential conceptual trap. Since "eco" has been so much used by those who promote and defend the natural environment, the use of this prefix may conjure up in some readers' minds images of the outdoors and protesting against global warming. Nevertheless, we suggest its use because of its conceptual elegance and origins.

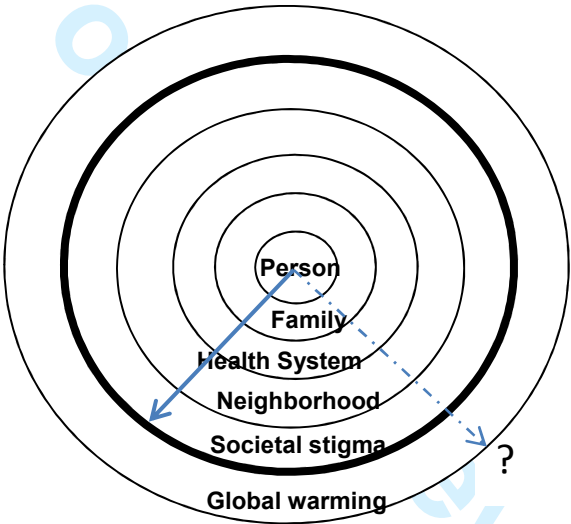
The term *ecopsychosocial* provides a significant improvement over the present term *nonpharmacological*, positively delimiting an expanding category of therapeutics and serving to draw together for research purposes a broad group of interventions to treat dementia.

The value of the *ecopsychosocial* terminology for the scientific community is that identifying a field with clear and, in this case, potentially broader boundaries and components should result in more fruitful professional collaboration and discussion, while providing a vehicle for structured research support. As the field of *ecopsychosocial studies* of cognitive decline and dementia is increasingly recognized, subject matter, academic curricula, and research protocols particularly suited to the field

are likely to emerge. Similarly, results of related research projects can more easily be compared—thus contributing to a critical mass of comparable data to be used in resource allocation and policy making.

**Determining the Range of “Ecopsychosocial” Outcomes**

Including environment as a factor raises the question of what scale or range of environment ought to be considered when defining the environmental context of *ecopsychosocial* interventions. What is the environmental range of the “dementia problem”? Figure 1 provides a conceptual diagram of the *ecopsychosocial* approach.



**Figure 1: Environmental Range of Ecopsychosocial Interventions in**

Clearly the person at the center of the diagram, his or her family, and their health system are part of the “dementia person’s” environment. But what about the neighborhood and larger community? Community resources are important because those living with dementia are more likely to use the physical and commercial environments near their homes and in their community if they feel welcome and if neighbors are trained to understand and respond to their needs. Social policies and practices need to resist the culturally defined social stigma associated with the disability, so that dementia is no longer a barrier to social integration.

Local government regulations that affect barrier-free streets, parks, and public transit as well as environmental requirements, codes, and standards for special-needs residential environments are directly relevant to the context within which people with dementia live. The argument can be made that urbanization, air pollution, the way our food is handled and sold, and global warming are all part of the dementia person's environment. However, expanding the definition of *ecopsychosocial* context beyond community and society runs the risk of diluting the discipline beyond practical bounds. We propose to include the study of social attitudes toward persons with dementia and the stigma associated with dementia, as well as social policies and investment in dementia, as relevant contextual limits at this time.

In summary, *nonpharmacological* approaches make up a dynamic and expanding field of treatment and research with positive effects on illnesses and diseases including dementia. The scientific and practice communities need better and more positive language to describe this growing field. While the term *nonpharmacological* emphasizes what the field is not and forces the definition to center in and around conventional pharmacological therapies, the term *ecopsychosocial*, incorporates environmental and contextual influences and emphasizes the importance and positive nature of a broad range of interventions in the lives of those living with dementia.

*Ecopsychosocial* is a practical and conceptually elegant term to replace the term *nonpharmacological* in dementia and other studies. *Ecopsychosocial* avoids defining phenomena by what they are not and, more significantly, includes the broad range of subject matter and research interest embodied within the overall term, such as contextual issues and environmental design. Every concept, including *ecopsychosocial*, needs to evolve through debate, research, and in this context, regulatory and governmental action. We urge and welcome the professional community's adoption of this terminology, as well as ongoing commentary and study of these matters.

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<sup>10</sup> This calculation represents 5% of the global figure of \$655 billion annual world-wide present expenditures indicated in World Health Organization (WHO) & Dementia Disease International (ADI) (2012), Dementia: a public health priority, World Health Organization, Geneva, Page 2, ISBN: 9789241564458.

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<sup>12</sup> Charras, K., Gzil, F. (2013). Judging a book by its cover: uniforms and quality of life in special care units for people with dementia. *American Journal of Dementia Disease and Associated Disorders*, Vol. 28, No. 5, 450-458.

<sup>13</sup> Benson, S. (2009) "Ladder to the Moon: interactive theatre in care settings." *Journal of Dementia Care*, Vol. 17, No 4, 20-23.

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